



Nursing Home Transitions in California

Produced by



The National
CONSUMER VOICE

for Quality Long-Term Care
formerly NCCNHR

April 2013

ACKNOWLEDGEMENTS

The Consumer Voice has many individuals and groups we wish to thank for their assistance in developing this report. First and foremost, we want to thank all of the consumers that participated in interviews. We also want to express our sincere gratitude to Mary Sayles of California Community Transitions and Lead Organization transition coordinators who worked with us to identify individuals for interviews. This report would not have been possible without these consumers, CCT staff and transition coordinators.

In addition, we'd like to thank the following people:

California "Quality Care, No Matter Where" Advisory Council

Janet Canterbury, Consumer Outreach & Legislative Advocacy, Personal Assistance Services Council of LA County, California Alliance for Retired Americans

Eric Carlson, Directing Attorney, National Senior Citizens Law Center

Karen Jones, Coordinator, Long Term Care Ombudsman Services of SLO

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Supported by a grant from The SCAN Foundation, dedicated to creating a society in which seniors receive medical treatment and human services that are integrated in the setting most appropriate to their needs. For more information, please visit www.TheSCANFoundation.org.

INTRODUCTION

In 2011, the National Consumer Voice for Quality Long-Term Care (Consumer Voice) started an initiative called *California Consumers for Quality Care, No Matter Where*. A major component of this initiative was to identify and advocate for one or more improvements in the home and community-based services system. In order to determine what issue to focus on in California, staff of the Consumer Voice conducted interviews with experts in the state who indicated that nursing home transition - the transition of a nursing home resident out of the nursing home and into community living - was an important topic that could benefit from attention and advocacy efforts. The California Advisory Council, consisting of representatives of both aging and disability organizations and programs, adopted this issue for its project work.

Overview of Nursing Home Transitions in California

California first began work on nursing home transitions in 2007 when the California Department of Health Care Services (DHCS) was awarded a grant through the federal Money Follows the Person Rebalancing Demonstration and continues today. The California Community Transitions Project spearheads transition efforts. The project identifies eligible Medi-Cal recipients who have lived in a nursing home for 90 days or longer and wish to move back into the community. The project then facilitates and monitors their transition. The state of California contracts with “lead organizations” that employ or contract with “transition coordinators” to assist and support individuals returning to the community.

Once in the community, individuals receive services, such as personal care and meal preparation, that are funded either through In-Home Supportive Services (IHSS) or the Home and Community-Based Services Med-Cal Waiver.

In-Home Supportive Services (IHSS) is designed to help the low-income elderly, blind, and people with disabilities of all ages live safely in their own homes if they wish to do so, rather than in a nursing home or other group care facility. IHSS pays for a wide variety of home-based services performed by home help workers, including non-medical personal care such as bathing, grooming, feeding, dressing or toilet assistance, and cleaning, laundry, shopping, cooking, and washing dishes. Under direction of a licensed health care professional, IHSS can arrange for paramedical services, or provide transportation to and from medical and other necessary appointments.

A Home and Community-Based Services (HCBS) Medi-Cal waiver is a special Medi-Cal program that waives certain Medi-Cal rules so that people can live at home instead of living in a facility. The waivers use the same Medi-Cal rules for counting income and property that are used for people living in a facility. Additional services are available under the waivers that are not ordinarily available under the regular Medi-Cal program for people living at home. Examples of these services include home modification, supplemental [or “extra”] personal care services, and additional home health services. This means that Medi-Cal beneficiaries can receive the services they need at home instead of having to go to a facility to receive them.(1)

(1) *Disability Rights California: How to Get the Extra Help You Need to Stay in your Own Home and Avoid a Long-Term Care Facility* (<http://www.disabilityrightsca.org/pubs/539201.pdf>). Between 2008 and 2012, 827 individuals transitioned out of CA nursing homes (<http://www.kaiserhealthnews.org/Stories/2012/May/24/states-obstacles-moving-elderly-disabled.aspx>). This number is far less than the goal of 2000 over five years set by the state in 2006 (<http://www.cms.gov/Regulations-and-Guidance/Legislation/DeficitReductionAct/downloads/StateMFPGrantSummaries-All.pdf>).

PROJECT GOAL

Moving from a nursing home back into the community can be difficult, particularly if an individual has been in the nursing home for many years and/or if the person is living with a disability for the first time. There are many factors that contribute to a successful transition, such as available housing and services and assistance from a transition coordinator. The purpose of this project was to identify, from the consumer perspective, ways in which individuals who have moved out of a nursing home believe the transition process could be improved and to recommend policy actions based on what we learned from consumers.

METHODOLOGY

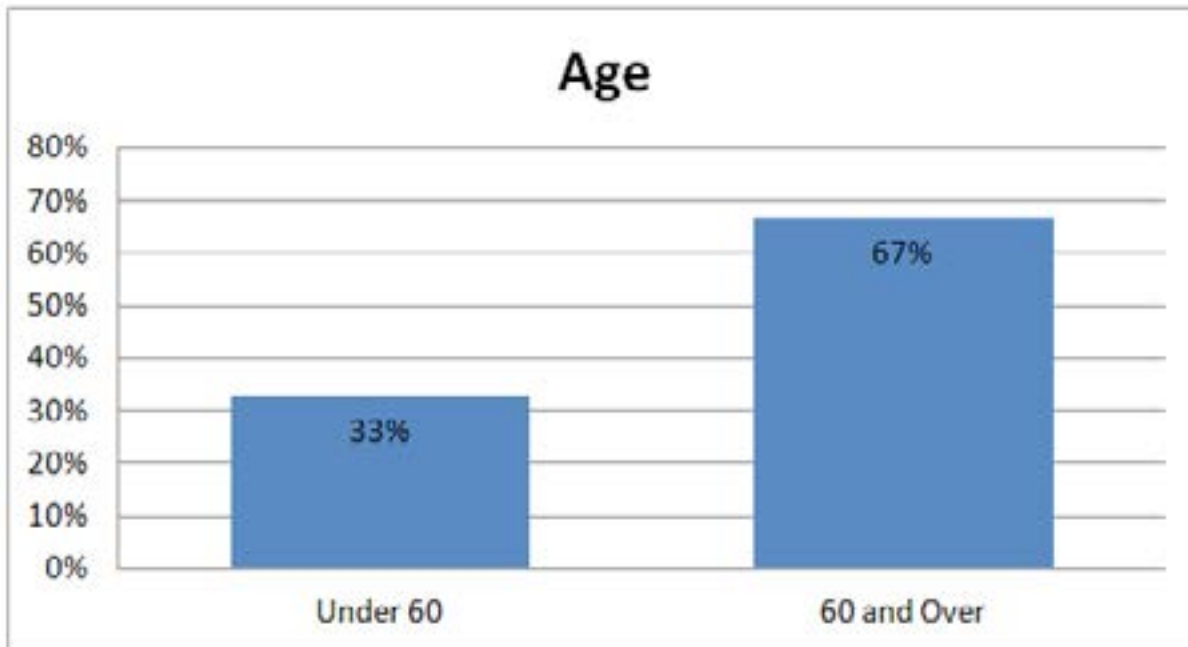
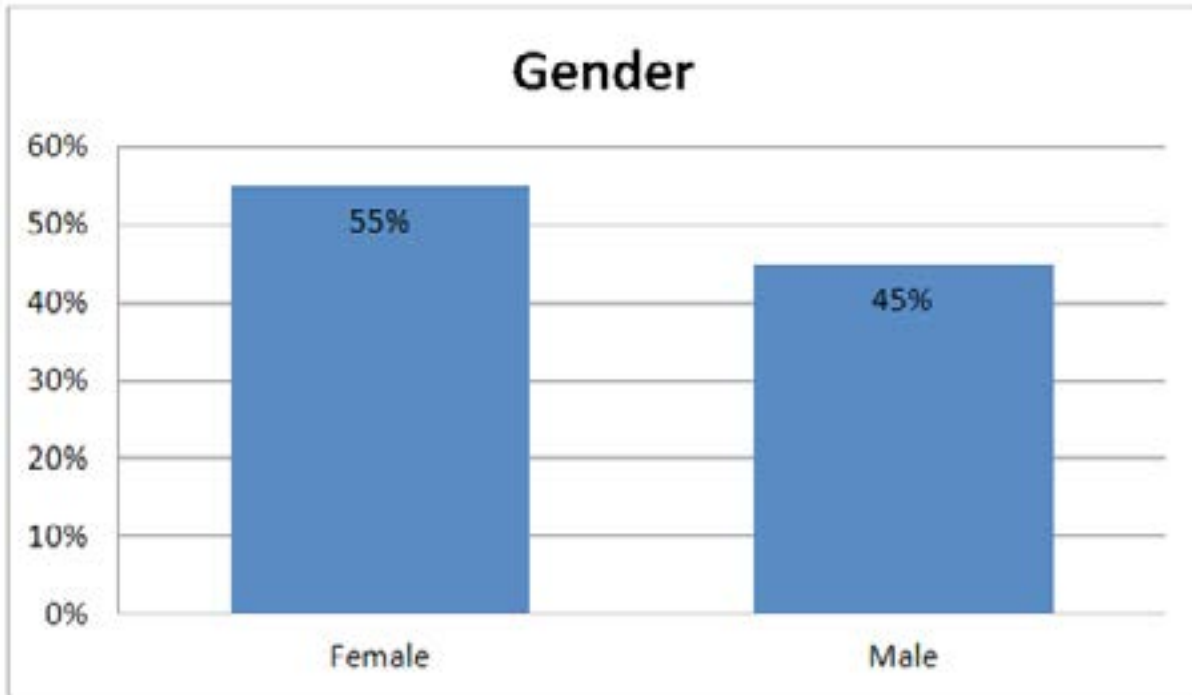
The California Community Transitions Program contacted transition coordinators who identified individuals who had successfully transitioned or in one case, were in the process of transitioning. After consent was received, Consumer Voice staff interviewed 20 consumers by phone. Staff developed questions with input from the California advisory council. The following questions were asked:

- How old are you?
- Why did you have to go to the nursing home?
- How long were you in the nursing home?
- How did you find out that you could move out through a program?
- How long did it take for you to move out of the nursing home – from the time you learned that you could move out to when you moved into your own place?
- When did you move out?
- What kind of housing did you move to? For instance, was it senior housing? Section 8 housing?
- Tell me what you did to move out. How did you get a place to live? Who helped you? What things did you have to take care of?
- Did you have to adjust to being in the community after living in a nursing home? If so, what adjustments did you have to make?
- What would have helped to make the move out of the nursing home and into your own place smoother?



Profile of Consumers

The majority of the consumers interviewed were female and over the age of sixty.

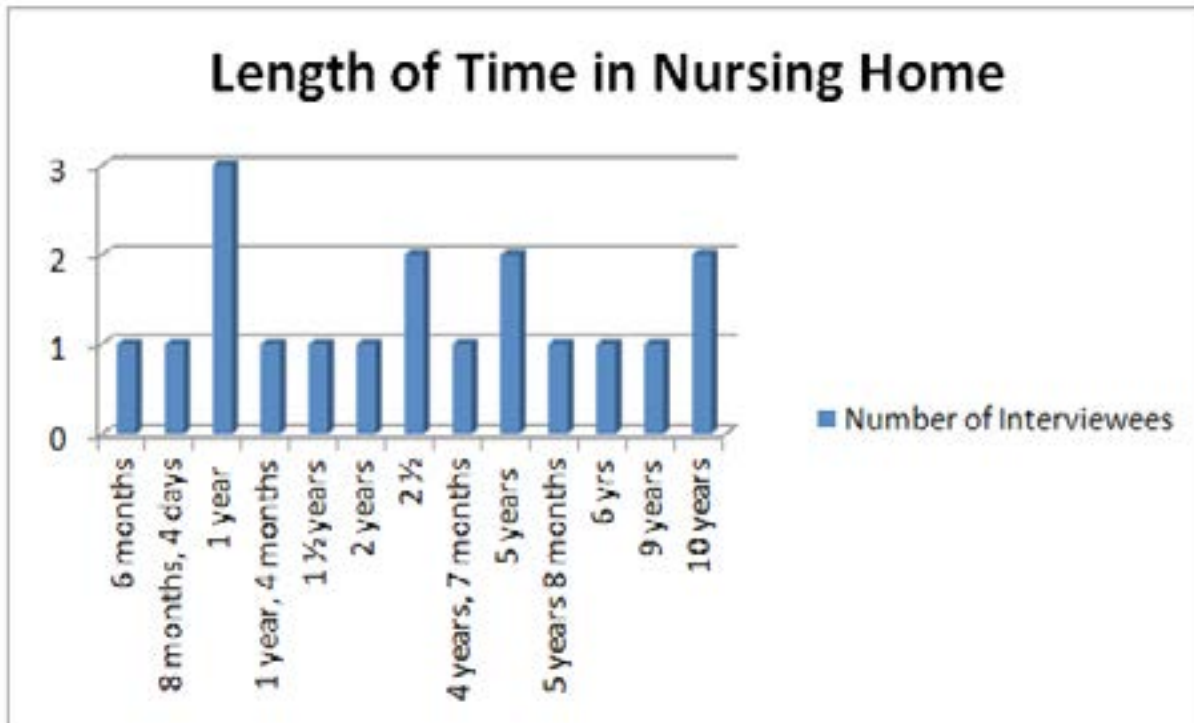


WHAT CONSUMERS SAID

Reason for Nursing Home Stay

There were various reasons the individuals we interviewed were in a nursing home. Fifteen of the twenty individuals said they came to the nursing home after a hospital stay. In addition, three individuals under the age of 60 moved to a nursing home after they were seriously ill in the hospital and lost the use of their legs. Moreover, two individuals over the age of 60 said they had to go to a nursing home after hospitalization because they had no one to care for them or did not want their children to care for them. Two individuals also stated they had been homeless prior to their nursing home stay

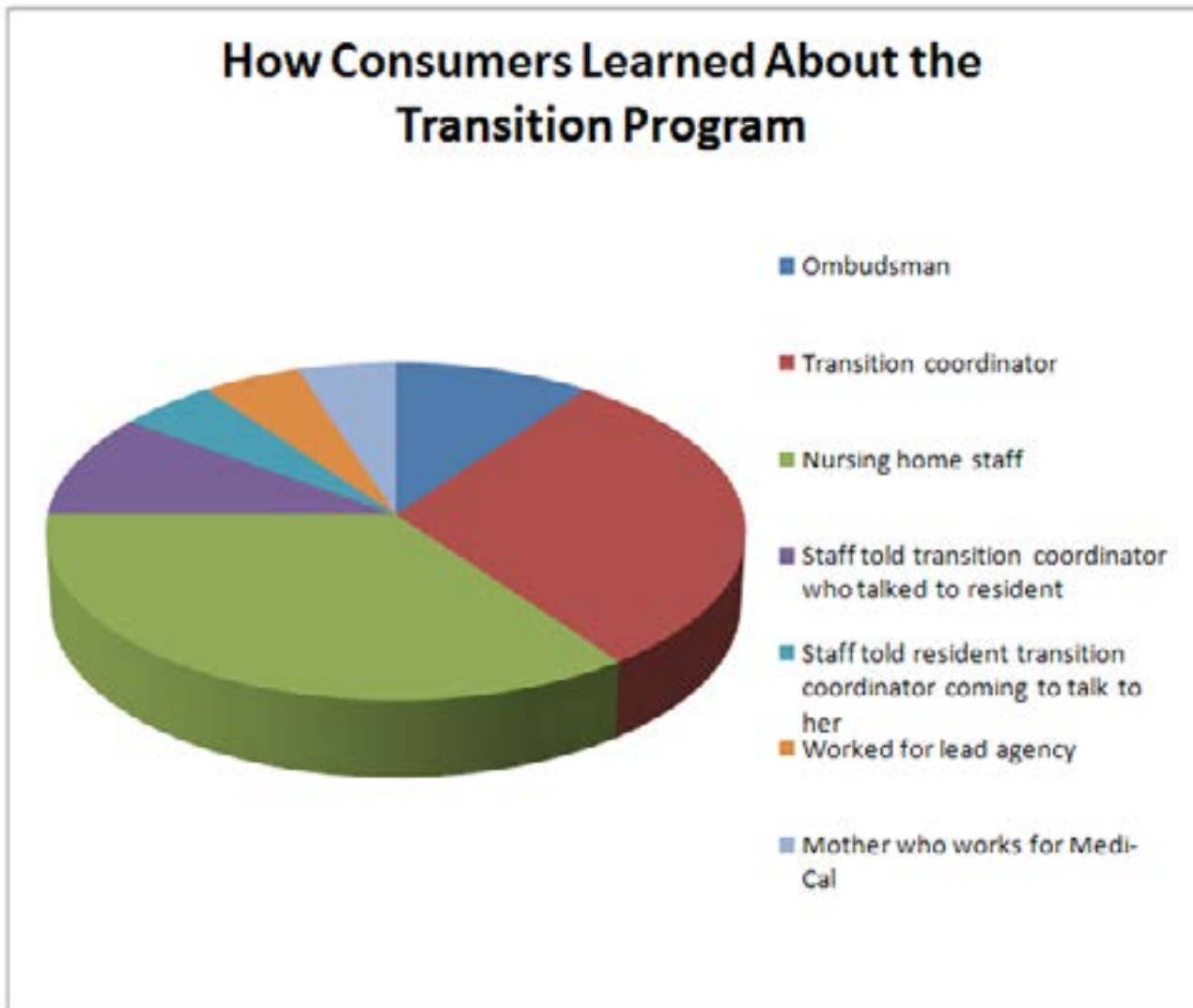
Length of Time in Nursing Home



Note: One interviewee had not yet transitioned out of the nursing home; one interviewee did not respond.

The average length of the interviewees' nursing home stay: 3.8 years

How Consumers Learned about the Transition Program



The vast majority of individuals - 16 out of twenty - learned about the nursing home transition program from either nursing home staff or the transition coordinator.

Assistance Provided to Consumers during the Transition Process

- Transition Coordinators Were Instrumental

Consumers across the board stated that their transition coordinators were instrumental in explaining the transition process and helping them move out of their nursing homes. One consumer said that the transition team did “everything” for her and that they “really bent over backwards.” The list of tasks the transition coordinators helped with is extensive.

Housing. A major area where transition coordinators assisted consumers was with housing. The coordinators helped locate appropriate housing by either finding the apartment, taking the consumer to view apartments, or helping the consumer determine what modifications were needed inside their apartment. Some modifications included the installation of a septic tank and a fire alarm, as well as making the apartment more accessible by adding ramps and handrails.

Furnishing the Apartment. Transition coordinators helped furnish the new apartment by either picking out furniture or actually furnishing the apartment for the consumer. Items purchased by transition coordinators included linens, towels, pots and pans, silverware, table, chairs, lamps, a microwave, coffee pot, and utensils. Coordinators arranged for delivery of beds and refrigerators if necessary and worked to obtain items consumers needed such as food, medications and medical supplies.

Moving. Transition coordinators helped consumers move the day of the relocation.

Financial. Some consumers reported that transition coordinators helped pay for the security deposit and first month's rent.

Hiring Caregivers. In a number of cases, transition coordinators selected caregivers for the consumer to interview, arranged the interview process, brought in candidates for the consumer to interview, and one transition coordinator even found a caregiver for the consumer. Furthermore, a transition coordinator also assisted the consumer in conducting the interviews.

Follow-Up Assistance. Some transition coordinators performed follow up assistance such as checking on the consumer once a week by phone, or continuing to take the consumer to their doctor appointments after they had moved out of the facility.

Nursing Home Staff and Family Members Also Aided Consumers

In some instances, consumers noted that nursing home staff and family members helped them with the transition process. For example:

- The nursing home social services designee took a consumer to view apartments.
- Nursing home staff taught a consumer how to ride a bus and to cook.
- A nursing home administrator and maintenance person delivered boxes of belongings to one consumer's new apartment.
- Nursing home staff offered support and encouragement throughout the transition process to one consumer.

Family members were also helpful to consumers when they transitioned out of a nursing home. One consumer's family helped move her belongings into her new apartment and gave her items to decorate it. Another consumer's family member filed her housing application for her. One consumer said that his family was particularly helpful with his transition, and noted that it would have taken a lot longer for him to transition without the assistance of his family. For instance, "if medical equipment is to be delivered, someone has to be there. It would take a while for a transition coordinator to be able to find the time to be at the apartment for the delivery." Other family members helped consumers find housing, paid their deposit, and got the utilities turned on.

Other Factors that Helped Make the Transition Easier

One consumer became involved in a Center for Independent Living and took a class on "living with disability." The class taught him, as a double amputee, how to carry out activities and deal with issues that come up. Another consumer found it enormously helpful to have the new caregivers he had hired come to the nursing home two days before he moved to help him pack up. This allowed him and his family a chance to meet and get to know the workers, which made the transition easier.

BARRIERS CONSUMERS FACED DURING THE TRANSITION PROCESS

Figuring Out How to Get Around

One consumer noted that a barrier to transitioning out of the nursing home was figuring out how to get to all the places she needed to go. For example, the consumer needed to look at apartments and obtain a copy of her birth certificate to get an ID. She was able to navigate the public transportation system and learned how to use the bus, but it was expensive and she had to spend her own money. In addition, this same resident was mistakenly ordered a manual wheelchair instead of a power wheelchair. After she transitioned, it took her an hour to wheel herself to the closest pharmacy.

Difficulty in Hiring Caregivers

A number of consumers noted how difficult it was to hire caregivers. Consumers who were not familiar with receiving care prior to living in a nursing home noted not knowing how to hire/select a worker, what the workers were responsible for doing, how they got paid, and what the consumers could expect from them. Consumers discussed not knowing what questions to ask when hiring caregivers. One individual mentioned that the information sheet they received from IHSS did not provide him with specific questions he could ask. Some consumers found it difficult to cold call “strangers” and determine how to choose someone on their own.

Consumers also experienced problems in finding caregivers. Only one person mentioned using the IHSS registry, although he had no luck. Others found it difficult because they did not have Internet access while in the nursing home, could not get to a public library to use a computer and could not place an advertisement because it cost money. There was even one person who began to think he would not be able to leave the nursing home because he had such trouble obtaining a caregiver.

Trouble Locating Appropriate, Available and Affordable Housing

Multiple consumers we interviewed also noted they had a hard time locating housing. For one consumer, locating a place to live became a “full time job” and he had to spend the majority of his time searching for an apartment. This consumer described the process of finding an apartment as “awful.” The primary problem he and others faced was the expense. Most apartments cost too much for Medi-Cal recipients, limiting them to low-income housing. However, subsidized housing is very limited and consumers faced long waiting lists. The same consumer mentioned above said he called the housing authority every week in order to see if there was an apartment available. Finding an available apartment that was wheelchair accessible was yet another problem. One consumer took an apartment that was not wheelchair accessible in order to find a place to live and then needed to have it modified.

Not Being Prepared to Live Independently

One consumer noted that because he did not have much physical therapy in the nursing home, he was not adequately prepared to live independently. He had no prior experience living with a disability and was recovering from septicemia, heart and kidney failure and the loss of the use of both his legs. He had not learned how to get in and out of the shower, on and off the toilet, or in and out of the car while at the nursing home. Other consumers said they did not know how to manage tasks like managing a budget or planning and preparing meals.

Securing a Doctor Who Accepted Medi-Cal

One consumer interviewed said the “worst” barrier to transitioning was finding a doctor. Finding a doctor was a stipulation to him transitioning back into the community; therefore, he would not be able to leave the nursing home until he had secured a doctor and made an appointment. This consumer noted that it was very tough

to start this process because he did not have a list of doctors from which to choose. Additionally, since he had no access to a phone in his facility, it was very difficult to call numerous offices to see if they were accepting new Medi-Cal patients.

Lack of Support

Although many consumers we interviewed stated how helpful the transition coordinators were, others stated that no one from the transition program helped them.

ADJUSTMENTS TO LIVING IN THE COMMUNITY

Enjoying Privacy, Independence and Choice Again

Consumers expressed how wonderful it was to have moved out of the nursing home.

One consumer noted that her biggest adjustment was finally having privacy again. In a nursing home, her whole life was “three inches beyond the edges of her bed.” However, in her own apartment, she could now watch television without someone telling her to turn it off. In addition, she had “the power of choice”. She could make her own plans and not live her life according to someone else’s schedule. She could also choose the type of food she wanted to eat, even if it were just a quick sandwich. This consumer calls this time in her life her “second adulthood” now that she has finally become “officially independent.”

Another consumer said that he was happy for the privacy and that he would not have to worry about someone waking him up at night to take his blood pressure or give him medications; or walk in on him in the shower. This consumer also liked to be able to cook his own eggs in the morning, since the nursing home never was able to get it right.

A third consumer stated that he “has a life again” and feels like he’s “alive again.” He said that the nursing home “sucked all the life out of him.” In the nursing home, staff made all decisions for him, such as when the television would be on, etc. The nursing home called, “all the shots.” The consumer said, “Now I’m the shot caller!”

Overcoming Feelings of Isolation, Helplessness, and Depression

Despite feelings of independence, many consumers talked about how difficult it was to adjust to not being around many people. Once consumers transitioned they were completely isolated, or their only companionship was their workers or pets. For a number of individuals, it was not easy to transition from living with seventy other people to living with only one person. Several consumers noted how quiet it was once they moved out of the nursing home. One consumer noted that their apartment was “scary quiet” after living in a nursing home. To counteract the quiet, another consumer sewed on her sewing machine, which filled the void and gave her something to do. One consumer said his feelings of isolation caused him to begin hallucinating and he ended up in the hospital for a short time. Another consumer noted that she missed some of the residents and staff at the nursing home and has been back to visit them.

Many consumers mentioned that they felt depressed when they first started living on their own. To counteract his depression, one consumer started helping other tenants in his building, and now runs errands for eight people. Another consumer noted he was nervous about staying off drugs and being sober and clean since he felt so protected in the nursing home.

Consumers also said how scary it was to be alone with no one there to help around the clock. Since everything is done for residents in the nursing home, it was difficult to transition to being on their own and needing to take

care of themselves. Consumers mentioned that it took a while to realize that someone was not coming in to help whenever they needed it. One consumer noted that he had to adjust to the fact that he “no longer had a call light.”

Establishing Own Schedule/Structure

Consumers expressed difficulty in no longer having a set routine or schedule. Consumers told us they had become used to the regimentation and strict schedule in a nursing home. One individual stated that it took a while to establish his own schedule and routine and to “learn how to do things on my own again.” Another person said that at the nursing home there were programs, like arts and crafts, to occupy his time, but, “when you moved back home, you had to rely on yourself for entertainment.” This same individual commented that at home there are no tasks to occupy his time since his worker does everything for him.

Difficulty Getting Around

Another adjustment for consumers was figuring out how to get around in order to carry out tasks like buying food, picking up medications from the pharmacy and even checking the mailbox. One woman, who had been in the nursing home for two years after a bad car accident, had to adapt to not having a car and thus the ability to go wherever she wanted, when she wanted. She also had to learn to use public transportation for the first time. Individuals with a new disability had to adjust to living in a wheelchair outside of a nursing home setting. One consumer said it felt like he faced one obstacle after another when using a wheelchair.



CONCLUSION AND RECOMMENDATIONS

The consensus of consumers interviewed for this report was that the transition process went very well. This appears to be in large part due to the work of the transition coordinators. Transition coordinators were involved in every aspect of the move out of the nursing home and back into the community. As noted earlier, they helped to find housing, arrange for home modifications, furnish the apartment or house, and pay for the rent and security deposit. They assisted consumers in buying food and medications and obtaining medical equipment. Transition coordinators found caregivers for individuals to interview and when needed, taught people how to interview and select their providers. On moving day they rolled up their sleeves and helped pack boxes and transport individuals. After the move, they continued to provide assistance and support.

The role of the transition coordinator is critical to the success of the move. The coordinator must be knowledgeable about long-term services and supports, housing and payment systems, including Medi-Cal. He or she must be adept at completing and coordinating an enormous number of tasks. A coordinator must also be very “hands-on” – ready to do whatever it takes from driving people to appointments to decorating apartments. The coordinator is a facilitator, a coach, a mentor, and a counselor.

While clearly indicating that the process was successful, when asked what would have helped make the move out of the nursing home and into their own place smoother, consumers had a number of ideas based on their experiences. We make the following recommendations based on a Consumer Voice analysis of the interview responses, as well as specific suggestions expressed by consumers themselves. Recommendations directly from consumers are indicated with an asterisk.

Preserve and Expand the Role of CCT Lead Organizations

Many consumers noted that the support they received from their CCT provider was invaluable to their successful transition. Here is what individuals who had transitioned said about their coordinators:

- Ms. S: The transition coordinator was great!
- Mr. O: The transition coordinator helped with the entire process. The transition coordinator assisted with the paperwork, interviewed him ... and checked their home to see what was needed for Mrs. O when she came home.
- Mr. C: The transition team helped with the complete move and arranged for his wife to move out with him.
- Ms. A: The transition team told her they would find her a place to live and help furnish it. Ms. A said she was skeptical, but it happened! ... Ms. A said that the transition team was wonderful. They “really bent over backwards” and did “everything perfect.”

Those who did not receive adequate support from a CCT provider expressed a desire for more assistance of this type. Consumers’ responses showed that the work CCT providers did was challenging and requires significant expertise and familiarity with local resources.

Maintenance and expansion of the CCT LO expertise is particularly important as many dually eligible Californians will soon start receiving coverage for long term care needs through new Medi-Cal managed care plans, as part of the state’s planned Coordinated Care Initiative. While the state has indicated that it intends for these plans to work together with the CCT program, it has not made transition assistance a mandatory benefit of Medi-Cal managed care.

Preserve and Expand Access to Medi-Cal Waiver Services

Medi-Cal waivers allow seniors and persons with disabilities to receive more home and community based services than might otherwise be available through the Medi-Cal program.

Provide More Detailed, Written Information about the Transition Program*

Consumers noted that it would have been helpful to have something in writing about the transition program. While we recognize that consumers may have received such information, they nevertheless felt as if they had not. One consumer felt that this information should include what exactly is going to happen, the steps you will be going through; how the transition coordinator can help; when the consumer will need to make decisions; clarifications about expectations; and how to interview and hire a caregiver.

Because multiple consumers stated that it would be helpful to have a checklist of the steps they need to take when transitioning, we recommend the creation and distribution of such a checklist to every consumer in the transition program. This would empower consumers during the process and better prepare them for what they will need to do.

Offer a Support Group for People who Transition*

Consumers repeatedly mentioned needing support during and after the transition. One consumer said that since there are so many issues that arise when people transition, a support group would be helpful for those who do not have family nearby to help. Another consumer noted that it would have been helpful for someone to be a “sounding board to help him through trying times.”

Such a group would allow people who are transitioning to connect with and gain support from others going the transition process.

Offer Peer Mentoring as a Paid Service During and After the Transition or, in the alternative, a “Buddy System”

Connecting with someone who has already successfully transitioned to the community can be a powerful source of support and assistance to a consumer who is moving back into the community from a nursing home. A peer mentor can provide the consumer with suggestions and ideas based on his/her own personal experience and first hand experiences – something a transition coordinator cannot do. Peer mentors can also provide knowledge, information and understanding while creating a meaningful and supportive relationship during this transitional process. This relationship can be particularly important following the move out of the nursing home since a number of interviewees indicated it was difficult to be by themselves in the community after being around many other people in the facility.

If a paid peer-mentoring program is not feasible, a type of “buddy system” should be created to connect a consumer who is transitioning to a person who has already transitioned. This would help provide practical advice, guidance as well as emotional support and encouragement.

Offer Training to Consumers Before They Leave the Facility*

Many consumers felt that it would have been beneficial to have training prior to leaving their nursing facility. They recommended a program or training to better prepare people to take care of themselves and live without having someone there to help them 24/7. Consumers said this was important because “everything is done for you in the nursing home.”

“I didn’t have to worry about paying for cable or grocery shopping in the nursing home.”

“A lot of times I didn’t know what to make or fix to eat. I only knew how to do things the way the nursing home did them.”

Interviewees believe trainers should include the following topics in a training:

- Menu planning and meal preparation
- Personal care e.g. how to bathe by yourself
- Paying bills and managing your own money
- “What you will have to deal with”

In addition, consumers said that a class would be helpful to try to prepare a person living with a new disability how to live as independently as possible. One consumer recommended having someone accompany the consumer to their apartment ahead of time to best show them how to move around in a wheelchair. Specifically, respondents thought the consumer should be taught how to get on/off the toilet, in/out of the shower/, in/out of the car; how to perform some of the cooking, laundry, and other tasks with a disability; and how to pick things up off the floor.

Training would increase consumers’ independence, self-reliance, self-esteem, confidence and quality of life as well as make it more likely that transitions will be successful. Training could be provided by the Independent Living Centers (ILCs) or modeled after the ILCs’ community living skills trainings. In addition, IHSS hours could be authorized to cover teaching and demonstration, to enable consumers to perform services for themselves.

Provide Assistance When Hiring Caregivers*

Many interviewees noted that finding potential caregivers, interviewing them and determining who to hire was difficult for them. Consumers expressed the need for a range of assistance when hiring caregivers.

To address this need, consumers, upon request, should be trained how to look for, interview and select caregivers. A few individuals indicated that their transition coordinator helped them in this way and it was extremely helpful. This approach provides consumers with experience while giving them someone to coach them through it. IHSS workers could provide this training since consumer education about interviewing and hiring caregivers is an IHSS responsibility. Alternatively, transition coordinators – who have developed a relationship with their clients - and also could coach them through the process.

In addition we recommend that transition coordinators give each person moving out of the nursing home a hard copy of the IHSS “Consumer Training Handbook,” which lists specific questions individuals can ask when interviewing a potential provider. Transition coordinators should also emphasize and inform consumers numerous times about the availability of the IHSS provider registry.

Offer Individuals who are Transitioning an “Onsite Experience” to Practice Living on their own Prior to the Day of the Move

A trial visit to the individual’s new home would make the move into the community go more smoothly. This experience would give the person a chance to practice getting around in the new setting, learn how to work with the appliances if appropriate, and identify areas where adjustments or more training are needed. Such a visit would build the individual’s sense of confidence and make the transition to a community setting easier.

Extend the Transition Program*

Consumers believed that the transition program was not long enough to cover the length of time it takes a resident to fully transition. They felt that extending the transition program from one year to either 18 months or two years would be more appropriate. One consumer expressed concern about where he would go for help once the transition program stops in a year.

Promote Greater Consistency among Transition Coordinators

All consumers praised the work of their transition coordinators and were very grateful for their help. However, it was clear that some coordinators assisted more than others did. For example, as noted above, one consumer said the only help she received with hiring caregivers was receiving an IHSS pamphlet, while other transition coordinators brought in caregivers to interview and guided the consumer through the process. Every consumer should have access to the same level of service and assistance.

Create a Group of Consumers who have Transitioned to Advise and Provide Feedback to the California Community Transitions Project (CCT)

These consumers could either join the existing Transitions Advisory Committee or serve as a stand-alone body. The goal would be to serve as a sounding board to CCT from the consumer perspective as CCT considers changes in the program or its services. Consumers could provide recommendations and suggestions based on their first-hand experience.





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